

Summary of ECD Global Alliance Internet Chat 31 August 2013

5 Attendees

- A member told us that she was “fighting” to get some financial support for transportation; because she is completely dependent on her car. Financial support has been refused. It was said that she should just take her time, and would be able to take the bus, and that having her own car wasn't necessary. She is complaining about this.

She has recently started taking Fampyra, a drug used by MS patients and referred to as “the walking pill”. This makes her a little steadier. She is working on a poster presentation about this new medicine for the San Diego meeting.

- A member, who likes to do wood-turning, has been able to do some work, but not as much as he wanted to do. The ECD had slowed him down.
- A US member is in the process of moving house. He is nearly done, but has to go back to his old house to “sell and get some stuff”. His wife is finding the driving back and forth quite tiring.
- Other members said that they were not driving now, and that their carers ended up doing it all. 2 members were still able to drive themselves.
- A member, whose son has ECD, told us that he will leave on Tues. for his 6 month check up in Houston, TX with Dr. Janku.
- A member, from the UK, told us that Dr Haroche (from Paris, France) had e-mailed this week, to ask whether the member had got a BRAF test result yet. This test is still to be done, but his UK doctor is finding out whether the lab samples that they already have, can be tested. Otherwise another bit will have to be cut off!
- The problem of having swollen feet was raised. One member’s feet get so “tight” they are numb. Another member said that they did have this problem sometimes, particularly when sitting a lot and having little exercise.
- A member’s wife has changed her work pattern, and is now spending quite a lot more time at home. She is still working about one day a week, on average, and this keeps her in touch with friends, and with work, while not having to do so much!
- We then discussed Public Holidays. The UK does not have any more holidays until Christmas. The US had Labor Day on the first Monday of September, and has Thanksgiving to look forward to in November.